The Royal Commission into Aged Care Quality and Safety
Via email to: ACRCsolicitor@royalcommission.gov.au

25 November 2019

Dear Royal Commissioners,

Re: Canberra Hearings – interface between the aged care and health care systems

About ADACAS

The ACT Disability Aged Carer and Advocacy Service (ADACAS) provides independent, individual advocacy to and with people with disability, people experiencing mental ill health, older people and carers. We adopt a rights-based approach to advocacy and also advocate in a systemic way to improve the systems and structures that affect the lives of people in the community.

ADACAS is a network member of the Older Persons Advocacy Network (OPAN), which delivers advocacy to people in aged care under the National Aged Care Advocacy Program (NACAP). ADACAS covers the ACT and some of its immediate environs. ADACAS is also a participant in the Aged Care Navigators trial, which aims to assist people who are having difficulty in accessing the aged care support they need through the My Aged Care (MAC) system.

Summary Statement

ADACAS has provided advocacy to older persons in aged care for over 20 years, and this brief submission is derived from the issues that we have assisted people to resolve over that period of time. It is also informed from the work we have done recently to engage with the Royal Commission, and with the Department of Health and the Aged Care Quality and Safety Commission (ACQSC), as well as our longstanding interest in an application of the practice of Supported Decision Making (SDM). Projects that ADACAS have undertaken, largely relevant to people with disability, have specifically addressed the problem of consent and decision-making in healthcare settings, and our learnings from this, as well as direct interaction with the The Canberra Hospital (THC) on issues related to decision-making and older people seeking to enter aged care, will also be addressed briefly in the submission.

Responding to the key issues raised by the Commission

ADACAS welcomes the focus that the Canberra hearings will take on the interface between the aged care and health care systems, and has some evidence from its Advocacy experience to address each.

The challenges faced by people living in residential aged care services attempting to access health services funded under Medicare or by the states and territories

There is a general problem about accessing healthcare services, as it often requires physically attending clinics which can be problematic for some older people who have mobility impairments. The lack of choice of practitioners will be addressed below, but denial of access to those who may know and understand the resident better due to a long-standing professional relationship could result in inappropriate diagnoses and treatment. This is turn can contribute to the problem of over-medication, a form of chemical restraint.

There is some evidence GPs do not visit RAFC's because they do not get paid.

Whether there is a need to improve access to primary health care services (particularly general practitioners, nurse practitioners and primary care nurses) for older people in residential aged care, and if so, how this could be achieved

There is a need because there are too many instances being reported of very poor health of some residents in some facilities. There have been situations where clients have urgent medical needs, which are not properly attended to and become even more problematic due to a lack of urgent medical attention. An example in the ACT was one older person in a RACF who developed a gangrenous infection on her leg, which became so bad that whenever people entered her room there was a very foul smell, which remained undetected for some time. The resident was eventually admitted to a hospital on an emergency basis and the notes that were made by the paramedic/medical staff stated that they were shocked at how badly the infection had developed and how the RACF had not properly attended to the wound.

We have had concerns from time to time that the medical condition of clients has become so bad we believe that it may have significantly contributed to the death of the older person, due to lack of appropriate treatment being given and/or in a timely fashion. One instance was particularly shocking when after the death was reported it was found that the resident had abscesses in her mouth.

ADACAS suggests that:

- Access to primary health care should be a priority in regards to prevention and promotion of wellbeing of nursing home residents. There should also be choice in the providers of these services.

- As described in the examples many of these scenarios could have been avoided if appropriate access to primary care services such as primary care nurses, physiotherapists, occupational therapists and social workers.
- All aged care staff need to be better trained in basic principles of good nursing care in the prevention of bed sores and other injuries.

Whether there is a need to improve access to high quality secondary and tertiary (sub-acute and acute) health care services for older people in residential aged care, and if so, how this could be achieved.

Definitely, this should be done. We can achieve this by RACFs doing the following:

- RACF staff should receive training in when to differentiate between a wound/medical condition that can be treated in an RACF and when a person needs to enter a hospital;
- There needs to be better and more regular access to registered nurses in RACF
- We need to ensure that the voice of the older person is always listened to and remains at the centre of each decision made, to the greatest extent possible. This situation can be improved by providing Advocates to the older people and by making use of a supported decision making model (see the SDM section below) when medical supports/decisions involving the older person need to be accessed/are made.

There is a need for State and Territory run health care systems to better interact with RACFs and people receiving aged care in home, and to make available pathways that facilitate easy access to secondary and tertiary health care services, to some extent addressed by the provision of patient transportation.

Examples:

1) An elderly lady fell from her bed and was not found until the morning and found to have broken her scapula bone. She was put back into bed with the broken bone. She was not sent to hospital until much later in the day where she was found to have a broken scapula and dislocated her arm. She was in terrible pain. A couple of days later the staff had the wrong arm in a sling and the injured arm hanging down by her side, she was in extreme pain.
2) An older man with Multiple Sclerosis, bedbound with a urinary catheter and bag. The catheter bag had not been emptied for some time, the urine backed up into his kidney, causing sepsis, eventually causing his death.

3) An elderly lady had an eye infection, the family asked for her to be sent to hospital. The RACF declined, saying they could treat it. The infection got worse and the family sent for an ambulance to take her to hospital. The infection was so advance she had to have the eye removed because it could not be saved.

The challenges faced by people living in aged care in accessing medical specialists, and the harms arising from inadequate access.

It is our experience that in some RACFs management limits the choice of medical professionals that an older person can have access to. Instead, they often have an arrangement with a GP and other medical practitioners who will come and visit all the residents. Evidence would suggest that there are healthcare benefits to all people, including older people, to maintaining a longstanding relationship with, especially GPs, so this practice does not only restrict choices but has the capacity to compromise people's overall level of health and wellbeing. There is a concern that as the GP has entered into an arrangement with the RACF, there might be a conflict of interest, whereby the GP is more interested in representing the viewpoint and interests of the RACF rather than that of the patient/older person living in the RACF. This is contrary to the Charter of Aged Care Rights, and is not consistent with the principle of consumer directed care, and something we would expect to be considered negatively when RACFs are being assessed against the Aged Care Standards.

The above relates to other medical services, such as dental, with the inconvenience of having to organize transportation and staff to assist and accompany residents being cited as the reason why RACF management prefers residents to utilise in-house practitioners (namely those which are contracted directly by management for the use of all residents). If residents have mobility impairments which preclude them from accessing external practitioners independent of RACF staff, then it is our experience that the choice of external practitioners is denied by management.

Whether it is necessary or desirable to improve how older people are transferred to and from aged care and hospitals, including the appropriateness of rehabilitation and transition care services post hospital attendance

In ADACAS' experience the following points are relevant to this issue:

- Transport home from hospital has been an issues for some residents. We have examples of people being put in a taxi and send back to the Nursing home after a visit to hospital
- There is often a lack of or no post hospital rehabilitation
- There is little or no transition of care following hospital treatment

There are not enough rehabilitation services for older people. Older people need a longer time to recover than younger people and insufficient time or supports are provided to older people in general to help them rehabilitate and recover.

Whether there is a need for improved data collection, communication and planning in relation to the health needs of older people accessing aged care services, including the interoperability of care management systems

In general there is a need for greater operability across systems which are administered separately and by different jurisdictions, and, in this case, a system which genuinely places the individual at the centre and works around that person's needs and preferences. This presents a challenge in the development of systems that operate across existing administrative arrangements, and for the collation of reporting data which can provide a holistic view of the treatment provided to any one individual.

The sufficiency of access to state and territory funded palliative care services for people living in residential aged care

Our experience is that the RACFs in Canberra do access the excellent palliative care that is available in the area, and by and large they do an excellent job. We are in contact with staff who are palliative care specialists who confirm that the general experience of palliative care in the ACT is excellent, and that older people have access to this. This is not the case, however, in regional areas, where palliative care can be hard to access and people often struggle to be properly supported. More palliative care needs to be directed to regional areas, and hopefully the situation in the ACT will continue to be as accessible to older people. We have specific examples of how the care provided by the team here in the ACT was done with immense cultural sensitivity that led to a comfortable and calm passage to death.

In summary ADACAS believes that:

- Access humane end of life (Tertiary) care is critical. Often the nursing home make the decision what care is needed when a resident reaches end of life and will not seek medical advice, often left to die alone in their bed. Palliative care is often not an option except on occasions when the family makes the referral
- Palliative care should be available to all people at end of life

<u>Supported Decision-Making</u>

ADACAS has a developed expertise in the growing field of Supported Decision-Making (SDM), which we have been practising for over 9 years now through a series of funded projects. We have already made submission to the Commission, on the topic of Capacity, Guardianship and Supported Decision Making, as part of OPAN's series of submissions, in August 2019. In this submission we:

- Highlighted the problem that many older people face in respect of their decision-making capacity being questioned and their choices particularly limited, and that this tendency to question capacity and to in many instances invoke substitute decision-making process, denies the will and preference of the person when choices are made;
- Pointed to the institutional application of instruments such as Enduring Powers of Attorney (EPoAs) which are required as a rule by many RACFs in the ACT, and which can lead to difficulty when the resident's choices and decisions, if they involve funds, are overridden by the person (usually a relative) hold the EPoA); and the link between these practices and the financial abuse of older persons;
- The denial of agency and choice in everyday interactions within RACFs, which is often attributed to poor staff training and low staff ratios, and which impacts negatively on the health and wellbeing of those residents for whom choice is routinely denied.

In the context of health care, and its interface with aged care, it is well-known that older people who experience ill-health are frequently confronted with significant decisions that are needed to be made about treatment and also about their accommodation post-treatment. ADACAS has participated in consultations initiated by THC in the ACT that seek to address how older people make be transitioned successfully from hospital into a setting where appropriate aged care is provided. Currently this tends to be exclusively RACFs, with home-based aged care being treated just as discharge to home, but it is apparent that a process needs to be instigated within the clinical setting that facilitates decision-making for a person who may be temporarily incapacitated as a result of their illness, and their will and preference about their ongoing living situation be taken into account.

In ADACAS' view there needs to be much more emphasis on SDM being implemented as a good practice generally in RACFs, as a means to actively engage older people in making the everyday choices that affect their quality of life, and this needs to be extended to their experience of healthcare, both within the RACF and in setting external to it.

We appreciate your consideration of this letter. Please do not hesitate to contact me should you require further information. I look forward to having the opportunity to speak further with you about these and other issues.

Yours sincerely,

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